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Dental care among young adults with intellectual disability

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Abstract

Dental care among young adults with intellectual disability (ID) is poorly documented and largely unmet. By using population-based data from the Metropolitan Atlanta Developmental Disabilities Follow-Up Study, we assessed factors associated with at least one or two dental visits per year among young adults with and without ID. Significantly fewer young adults with ID (45%) visited a dentist at least once per year, compared with those without ID (58%). ID severity and the presence of co-occurring developmental disabilities predicted dental care use. Sociodemographics, daily functioning, societal participation, dental services, and dental health factors were examined as predictors of dental care frequency. Our findings can help focus efforts toward improving the frequency of dental care visits among young adults with ID.

Keywords

Dental care; Dental care for disabled; Intellectual disability; Young adult

1. Introduction

Intellectual disability (ID) is significantly associated with poor oral health (USDHHS, 2000). Although recent advances in medical care have contributed to a substantial increase in the life expectancy of individuals with ID (Bittles et al., 2002; Janicki, Dalton, Henderson, & Davidson, 1999), dental care remains an unmet need (Waldman & Perlman, 2002). A recently published systematic review of studies confirmed the existence of gaps in dental care among people with ID within different age groups (Anders & Davis, 2010). Individuals with ID are more likely to receive a lower quality of dental care, or are less likely to have had a preventive dental visit, compared with individuals without ID (Charles, 2010; Chi, Momany, Kuthy, Chalmers, & Damiano, 2010; Reichard, Turnbull, & Turnbull, 2001).

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Disclosure

The findings and conclusions of this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

A study among children aged 3–17 years show older age, better access to dental health professionals, higher educational and family socioeconomic status, and experiencing a favorable interaction with the medical system, have all been associated with better preventative dental care use, irrespective of their ID status (Chi et al., 2010). On the contrary, other studies have shown that increasing dental care costs, lack of dental insurance or financial resources to pay for treatment, access to information, and willingness and training among dentists treating children with disabilities have negatively influenced dental care (Dasanayake, Li, Chhun, Bronstein, & Childers, 2007; Schultz, Shenkin, & Horowitz, 2001; Stiefel, 2002; Wolff, Waldman, Milano, & Perlman, 2004). Although these factors might also influence dental care across different age groups, understanding of the predictors and barriers for dental care among young adults with ID is limited.

One of the key limiting factors for dental care access among young adults is that, in the majority of states, Medicaid dental coverage is terminated when an individual attains 21 years of age (Centers for Medicare and Medicaid Services, 2011). In recent decades, a shift toward inclusion of individuals with ID into community-based or independent residential settings has occurred, which has led to disruption of routine dental care services available previously within institutional residential settings (Dwyer, 1998). Thus, as young adults are transitioning from pediatric to adult dental care, those with ID are particularly vulnerable to dental problems. Dental care among children with ID until age 18 years has received much attention; however, information specific to young adults in the earlier part of their young adulthood (ages 21–25 years) is lacking. Using a population-based study, we examined the frequency of dental visits and selected associated factors that promote or limit dental visits among young adults with and without ID. The study also examined the frequency of dental care on the basis of severity of ID and co-occurrence of other selected developmental disabilities (DDs).

2. Methods

2.1. Study design

This study used a cross-sectional, population-based survey of young adults who resided in metropolitan Atlanta and were identified at age 10 years-old with selected developmental disabilities.

2.2. Study participants

Two data sources were used to identify eligible subjects for this study. The Metropolitan Atlanta Developmental Disabilities Study (MADDS), 1984–1990 (Yeargin-Allsopp, Murphy, Oakley, & Sikes, 1992) is a population-based, multisource, cross-sectional study of children aged 10 years, born in 1975–1977, and with at least one of five DDs (ID, cerebral palsy [CP], hearing loss [HL], vision impairment [VI], and epilepsy [EP]). Mothers of these children had to be residents of one of five Georgia counties (i.e., Clayton, Cobb, DeKalb, Fulton, or Gwinnett) during 1985, 1986, or 1987. The primary source of ascertainment of children with DDs was through special education records at the nine public school systems serving the five-county area. MADDS obtained information on type, severity, and presence of multiple impairments for children with DDs. A random sample of children aged 10 years

without any of the 5 DDs monitored who were born in 1975–1977 and whose mothers were residents of the same five Georgia counties were chosen as a comparison group.

The MADDS Follow-Up Study, 1997–2000, was a cross-sectional follow-up study that tracked a subset of the original MADDS cohort in young adulthood (age 21–25 years). Young adults in the MADDS Follow-Up Study were selected by using a stratified two-stage probability sampling technique to represent the DD specific prevalence estimates among the baseline cohort. These young adults were administered follow-up interviews with a participation rate of 65% among young adults with DDs (n = 511), and 62% among young adults without DDs (n = 124). Additional details are published elsewhere (Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2009). Data were collected by using a structured questionnaire administered in person (27%) or by telephone (73%) from participants or their parents or legal guardians (serving as proxies), depending on the degree of cognitive impairment of the participant. Interviews with proxies that had no knowledge of how often the young adult visited a dentist during a year were excluded (3%). The two data sources, MADDS and MADDS Follow-Up Study, were linked by a unique study identifier to create the data set used here. The linkage of the two data sources and use of the final data set were approved by the Institutional Review Board at the Centers for Disease Control and Prevention.

2.3. Surveillance case definitions

Surveillance case definitions used for the MADDS Follow-Up Study were determined at age 10 as a part of MADDS. ID was defined as an intelligence quotient (IQ) of ≤70 on the most recently administered psychometric test. In the absence of an IQ score and in the context of testing, a written statement by a psychometrist that a child's intellectual functioning was within the range of moderate to profound intellectual disability was accepted. Severity of ID was defined according to the following categories in the *International Classification of Diseases, Ninth Edition, Clinical Modification* (Puckett, 2003): mild (IQ: 50–70), moderate (IQ: 35–49), severe (IQ: 20–34), and profound (IQ: <20). The surveillance case definitions for CP, HL, VI, and EP have been published elsewhere (Yeargin-Allsopp, Murphy, Oakley, & Sikes, 1992). Young adults with ID were further categorized analytically into three groups on the basis of severity and selected co-occurring DDs: (a) isolated mild ID (MID), (b) isolated moderate to profound ID (MPID), and (c) multiple ID, including young adults with ID co-occurring with other DDs (multiple ID). The notation 'co-occurring DDs' used henceforth in our description shall include at least one of five DDs: CP, HL, VI, and/or EP.

This study examined different demographic characteristics, including use of income-dependent services (as a proxy for socioeconomic status [SES]) and education; and transition outcomes (e.g., employment, vocational services, and living arrangements) as well as daily functioning. With the exception of race/ethnicity and sex, all demographic, transition, and functioning characteristics were obtained from the MADDS Follow-Up Study.

2.4. Demographic characteristics

Race/ethnicity was reported for two categories: non-Hispanic white (referent group) and non-Hispanic black. Hispanic or other race and ethnic groups cannot be examined because of the limited sample size. Age at interview was calculated by subtracting the subject's date of birth from the date of the interview. Two age categories were examined in the current study: 22–23 years and 24–25 years (referent group). Receipt of services from one or more of the following government programs was used as a proxy for low SES: Women, Infants, and Children Program (WIC); Food Stamps; or Welfare, including Aid to Families with Dependent Children. Those not receiving any of these aid services formed the referent group. Educational attainment was classified into three categories: less than high school, high school graduate or general educational development (GED) diploma (referent group), and postsecondary education.

2.5. Vocational services

A dichotomous variable was created to measure vocational services if individuals ever received assistance from at least one of the following vocational rehabilitation services in the past: (a) job coaching or on-the-job training by someone who works for an employment support service, (b) job placement, (c) United States (U.S.) Department of Labor Job Corps, (d) training in job-seeking skills, (e) sheltered workshop, (f) supported employment, or (g) other vocational services, which includes vocational training through universities, private companies, sensory resource centers or clinics. Those not receiving any of these services formed the referent group.

2.6. Living arrangement

Responses regarding living arrangements were classified into the following categories: (a) living independently with roommate, spouse, or alone (referent group), (b) living with parents or relatives (including adoptive parents), (c) living semi-independently in a staffed apartment, transitional group home, family foster care, intermediate care facility, skilled nursing facility, jail or homeless setting, including streets, bus stations, missions, or shelters), and (d) all other or unknown.

2.7. Activity limitations

Five items were used to measure limitations in activities of daily living (ADLs). Study participants were asked how often they received help from another person for (a) bathing, (b) dressing, (c) getting in and out of bed or chairs, (d) using a bathroom, and (e) getting around inside the home. A response of "yes" or "sometimes or partially" to one of the five items was used to create a dichotomous variable to measure the presence of any limitation in ADLs (one or more versus zero). Five items were used to measure limitations in instrumental activities of daily living (IADLs). Participants were asked if they received help from another person for (a) fixing meals, (b) shopping, (c) paying bills, (d) using a telephone, or (e) doing laundry. A response of "yes" or "sometimes or partially" to one of the five items was used to create a dichotomous variable to measure the presence of any limitation in IADLs (one or more versus zero).

2.8. Dental visits

Dental care visits in the past were assessed by the question, “How often do you go to the dentist?” Response options to this question included (a) fewer than once a year, (b) once a year, (c) two times per year, (d) more than twice per year, (e) refused, or (f) don’t know. In our analysis, dental visits were examined for two frequencies of visits, (1) at least one dental visit per year versus fewer than one dental visit per year, and (2) at least two visits per year versus fewer than two dental visits per year.

2.9. Dental services

Location where dental care was usually received was determined by asking, “Where do you usually get your dental care,” with response options of (a) private or family dentist (referent group), (b) public health clinics, (c) dental maintenance organization, (d) institutional clinic, or (e) other. Dental care insurance was examined by classifying interview responses as (a) health maintenance organization (HMO) or private dental insurance (referent group), (b) personal funds (young adult’s own money or caregiver’s money or borrowed money), or (c) Medicaid or other public funds. An option also was provided to convey no recent care.

2.10. Dental health

Having a toothache or gum bleeding during the 4 weeks before the interview was assessed by using the following question: “In the past 4 weeks, have you been bothered by frequent toothaches,” and similarly for gum bleeding. Response options for these two questions were (a) yes, (b) no, (c) refused, or (d) don’t know.

2.11. Data analysis

First, differences in selected demographic and dental characteristics (including dental visits, access to dental services, dental care insurance, and dental health) were examined for young adults with ID overall and then stratified by level of severity and the presence of co-occurring DDs, yielding three subgroups, isolated MID, isolated MPID, and multiple ID. Pairwise comparisons were made with young adults without ID by using Pearson’s chi-square test of significance ($P < 05$). Dental care use in the past was measured as a visit to the dentist at least once during the previous year. Other studies have reported that people among the general population visit the dentist approximately twice a year (USDHHS, 2000). On the basis of the previous literature, the association between severity of ID or non-ID and frequency of dental care visits was examined for the following outcomes: (a) fewer than one versus one or more dental visits per year and (b) fewer than two versus two or more dental visits per year, using logistic regression to further examine the role of frequency of dental care among young adults with ID. The frequency of dental care visits was examined as the dependent variable with ID severity as the predictor variable. Those without ID served as the reference category. Both crude odds ratios (cORs) and adjusted odds ratios (aORs) were calculated by using logistic regression analysis. Multivariable associations were adjusted for all demographic and dental variables available for study.

Only selected groups of young adults for whom a statistically significant difference in frequency of dental care visits existed, compared with non-ID group noted in the previous

analyses, were further analyzed to understand the effect of demographic and dental variables in frequency of their dental care visits. Thus, three subgroups of young adults, including those with any ID (including all types of ID), isolated MID, and no ID were studied further. Bivariate associations between frequency of dental visits during a year (dependent variable) and all demographic and dental characteristics (predictor variables) were examined by using unadjusted analyses. cORs and 95% confidence intervals (CIs) were estimated by using logistic regression analysis, individually for one or fewer and two or fewer dental visits per year. In the final step, all variables that were significant in the bivariate analyses, for one or more of the three groups of young adults, were entered into the adjusted model during multivariable logistic regression. The association between demographic and dental variables and frequency of dental visits per year, while controlling for sex, race/ethnicity, SES, education, employment status, receipt of vocational services, limitations in ADLs, type of dental care insurance, and having a toothache during the 4 weeks before the interview was examined. In all our analyses, estimates were statistically weighted to adjust for the complex sampling design and thus represent the baseline MADDS population. SAS® (SAS Institute, Inc., Cary, North Carolina) callable version of SUDAAN® (Research Triangle Institute (RTI), Research Triangle Park, North Carolina) was used for analysis of the complex multistage, stratified, and weighted study sample (RTI, 2009). SUDAAN computes standard errors by using the Taylor series linearization methods to account for the unequal sampling fractions of the study design.

3. Results

Our study included all 244 young adults with ID identified by MADDSP, with or without other co-occurring DDs and 124 young adults without ID or other DDs. In the final sample of young adults with ID, 48% (n = 117) had isolated MID; 30% (n = 73) had isolated MPID; and 22% (n = 54) had ID and at least one co-occurring DD. Across all severity levels, young adults with ID differed significantly from those without any ID by demographic characteristics, dental visits, dental service use, and dental health.

Young adults with ID were more likely to be male, black, aged 24–25 years, less than high school educated, unemployed, not receive vocational services, live in a nonindependent setting, and have limitations in ADLs and IADLs, compared with young adults without ID (Table 1). Similar differences were identified between young adults with isolated MID, compared with young adults without ID; but additionally, young adults with isolated MID were significantly more likely to receive income-dependent services, compared with those without. The third group, young adults with isolated MPID, were more likely to be black, aged 24–25 years, less than high school educated, unemployed, not receive vocational services, live in a nonindependent setting, and have limitations in ADLs and IADLs, compared with young adults without ID; similar differences were noted for the group of young adults with multiple ID, compared with young adults without ID, also demonstrating that young adults with multiple ID were likely male, compared with those without ID (Table 1).

3.1. Frequency of dental visits during a year

Fewer than half (45.1%) of all young adults with ID reported visiting a dentist at least once per year, compared with 58.1% of young adults without ID (Table 1). The percentage of young adults who reported at least two dental visits per year was small for young adults with ID, compared with those without (25.4% versus 40.3%). A much smaller proportion of young adults with isolated MID visited a dental clinic at least once a year (28.2%) or at least twice a year (13.7%), compared with young adults without ID. For young adults with isolated MPID and multiple ID, no significant differences occurred in the reports of dental visits per year, compared with young adults without ID. More than half (53.3%) of all young adults with ID who received dental care used private clinics or family dentists, with a smaller proportion (21.4%) using public health or institutional clinics. Similarly, young adults with isolated MID, isolated MPID, and multiple ID were all more likely to have received dental services at public health or institutional clinics, compared with those without ID.

All four groups of young adults with ID differed significantly from young adults without ID regarding their type of dental insurance. Approximately 48% of all young adults with ID had Medicaid or other state or county funds paying for dental care insurance (Table 1), whereas the majority of young adults without an ID reported private insurance coverage for dental care, with only 5% reporting Medicaid as the primary source of their dental insurance (data not shown).

The reported occurrence of toothache (≤4 weeks before the interview) was not significantly different among the groups of young adults with ID, compared with those without; however, young adults with any ID (12.8% versus 5.7%) and those with isolated MID (14.7% versus 5.7%) were significantly more likely to have reported a gum bleed (≤4 weeks before the interview), compared with those without any ID (Table 1).

As presented in Table 2, young adults with ID had a two-fold risk of not visiting a dentist at least once per year (cOR = 2.1; 95% CI = 1.4–3.2) and a 2.5-fold risk of not visiting a dentist at least twice per year, compared with young adults without ID (cOR = 2.5; 95% CI = 1.7–3.8). The association weakened after adjusting for potential related factors. Young adults with isolated MID had an even greater risk for not visiting a dentist at least once per year (cOR = 3.5; 95% CI = 2.1–5.7) or twice per year (cOR = 4.3; 95% CI = 2.4–7.8), relative to those without ID. After adjusting for potential cofactors, the magnitude of risk reduced for at least one dental visit per year, compared with no dental visits (aOR = 1.2; 95% CI = 0.5–3.1) and for at least two dental visits per year, compared with fewer than two dental visits) (aOR = 1.9; 95% CI = 0.7–2.8). No significant increase occurred in the odds of dental visits among young adults with isolated MPID, compared with young adults without ID and young adults with multiple ID, compared with those without ID (Table 2).

3.2. Factors associated with dental visits during a year

Regarding unadjusted analyses (Table 3), we determined that among young adults with ID, the following factors were associated with not visiting a dentist at least once per year: being male, black, low SES, having less than high school education, and having a toothache during

the previous 4 weeks. Conversely, the factors that increased the likelihood of one or more dental visits were having postsecondary education, receipt of any vocational service, and having any limitations in ADLs). For young adults, including only those with isolated MID, significant factors associated with not visiting a dentist at least once per year were less than high school education and unemployment. Having a postsecondary education and receiving vocational services increased the odds of having at least one dental visit per year. For young adults without ID in the study, being male, black, and not having dental insurance significantly predicted fewer than one dental visit per year.

For young adults with ID in this study, significant factors associated with fewer than two dental visits per year were being male, black, having less than high school education, and having a Medicaid or other state or county funds for dental insurance (Table 3). Factors that increased the likelihood of two or more dental visits per year were postsecondary education, receipt of any vocational service, and having any limitations in ADLs. For young adults with isolated MID in the study, unemployment significantly increased the odds for fewer than two dental visits per year, whereas receiving postsecondary education or vocational services significantly increased the likelihood of having at least two or more dental visits per year. Lastly, among young adults without ID, being male, black, and not having dental insurance significantly predicted fewer than two dental visits per year. Age at interview, living arrangement, limitations in IADLs, location where dental care was received, and having a gum bleed during the previous 4 weeks were not significantly associated with the likelihood of having at least one or two dental visits among young adults with and without ID (data not shown).

Results from multivariable analyses for factors that predict at least one or two dental visits per year are presented in Table 4. Among young adults with ID, the majority of factors that were associated with fewer than one dental visit per year in unadjusted analysis remained significant after controlling for selected covariates. For example, male sex, having less than high school education, and having a toothache within the previous 4 weeks of the interview, predicted not visiting a dentist at least once a year, whereas receipt of vocational services and having limitations in ADLs predicted more than one dental visit per year. For young adults, including those with only isolated MID, less than high school education and having a toothache within the previous 4 weeks of the interview were significant predictors for not visiting a dentist at least once per year. But for young adults without ID, being male, black, and having personal funds (own or borrowed money) to pay for dental care significantly increased the odds of not visiting a dentist at least once per year, whereas receipt of vocational services predicted more than one dental visit per year.

Among young adults with ID, the majority of factors associated with one dental visit per year were also significant for two dental visits per year (Table 4). Factors that predicted fewer than two dental visits per year included male sex, less than high school education, and having Medicaid or other state or county funds to pay for dental care, whereas receiving vocational services or having limitations in ADLs predicted more than two dental care visits per year. For young adults, including only those with isolated MID, the sole factor that remained a significant predictor in adjusted analyses for increased likelihood of two or more dental visits per year was receipt of vocational services. Finally, for young adults without

ID, two factors, being male and having personal funds (own or borrowed money) to pay for dental care, significantly predicted fewer than two dental visits per year, whereas receipt of vocational services predicted two or more dental visits per year.

4. Discussion

As children with ID reach young adulthood, they often face a myriad of challenges related to receipt of adequate and integrated health and education supports while transitioning from pediatric to adult services (Chambers, Rabren, & Dunn, 2009; Cobb & Alwell, 2009). Unfortunately, when priorities for overcoming these obstacles are identified, dental care is often overlooked because of more pressing needs (Waldman & Perlman, 2002). Given that ID is one of the most common DDs, affecting approximately 1%–2% of school-aged children, attention is needed to better understand the frequency and correlates of dental care within this population as they develop into young adults. In our study, occurrence and factors associated with dental care visits during a year were explored for the first time among a population-based sample of young adults with and without ID. We determined that young adults with ID were significantly less likely to visit the dentist during a year, compared with their unaffected counterparts. Sociodemographic and dental care variables, including sex, race/ethnicity, education, receipt of vocational services, limitations in ADLs, type of dental care insurance, and having toothache during the 4 weeks before the interview (which might be an indicator for poor dental care in itself) were identified as significant factors that promoted or limited dental care among young adults.

Access to dental care is commonly defined as an ability to obtain and make use of dental services (Guay, 2004). Dental care use is frequently measured by asking respondents if they visited a dentist at least once during the previous year, with national estimates demonstrating that on average, individuals in the general population visit the dentist approximately twice a year (USDHHS, 2000). The lack of existing research on dental care among young adults with ID limited the comparison of our findings on frequency of dental visits in a year. Nevertheless, when compared with studies based on children aged ≤18 years with ID that examined the percentage of children reporting at least one dental visit during a year, our study finding of 45% was within the same range (39%–54%) (Chi et al., 2010; Macek, Edelstein, & Manski, 2001; Soni, 2011).

Selected demographic predictors were explored and identified as significant predictive factors for dental visits among young adults in our study, and these differed by the occurrence and severity of ID. These factors further varied by the outcome (one versus two dental visits per year). We determined that among young adults with ID, males were at a significant risk of not visiting a dentist. Other studies among children with ID aged ≤18 years or younger (Macek, Edelstein, & Manski, 2001) and youth and adults with ID aged 18–44 years (Pradhan, Slade, & Spencer, 2009) did not find an association between sex and dental care visits. A racial/ethnic disparity in reported dental care visits was noted in the unadjusted analysis of our study, but did not remain significant after adjusting for other cofactors. Other studies reported racial/ethnical disparities in dental visits where white non-Hispanic children with or without ID were more likely to have at least one dental visit in a year, compared with black non-Hispanic children (Chi et al., 2010; Macek et al., 2001; Soni,

2011). Because race/ethnicity is often used as a proxy for SES, we explored the role of competitive employment and educational attainment to further assess this association.

Although dental care visits in association with educational and employment status of young adults have not been examined previously, higher educational and SES of the family has been reported to predict dental care use among children in the general population (Chi et al., 2010; Soni, 2011). Results from our adjusted analyses revealed having less than high school education is a significant predictor for not visiting a dentist at least once or twice per year among young adults with ID and once per year among young adults with isolated MID. We also identified employment status as a significant predictor for not visiting the dentist at least once per year, particularly for young adults with isolated MID, but the association was not significant after adjusting for other cofactors. Although in our study only 36.5% of young adults with ID were reported to be employed, this finding converged with that from another nationally representative study of adolescents and young adults with disabilities, where 31% of subjects with ID had obtained employment (Carter, Austin, & Trainor, 2011).

We determined that young adults with ID who received vocational services were more likely to visit a dentist at least once or twice per year. Further, young adults with isolated MID were more likely to visit a dentist at least twice per year if they received a vocational service. A study using the National Health Interview Survey (NHIS) data reported that 72% of working adults aged 18–65 years who had self-identified as having an ID received at least one or more vocational services during their lifetime (Olney & Kennedy, 2001). Receipt of vocational services was greater among those with ID if they were males, aged 25–44 years, white, not living independently, high school educated, and had limitations in ADLs and IADLs (Olney & Kennedy, 2001). In our study, 59% of young adults with ID had received a vocational service; and among those, the majority was male, black, high school educated, and had limitations in ADLs. The association between these predictive demographic factors for the use of vocational services among young adults with ID might explain, in part, the association we identified between vocational services and dental care visits. Further, young adults receiving vocational services might differ from their counterparts with respect to increased parental supervision, ability to access health care and personal grooming skills for seeking employment (M. Blanding, Atlanta Regional Office for Vocational Rehabilitation, personal communication, February 22, 2012).

Living arrangements or residential factors have been examined in relation to dental care use among individuals with ID. A Swedish study compared dental health status of children with severe ID to that of control subject children and reported that children with severe ID living in an institutionalized setting reported better access to dental care and had a lower prevalence of caries, compared with children with ID living in a community-based setting or control subject children (Forsberg, Quick-Nilsson, Gustavson, & Jagell, 1985). Adults with ID were also significantly less likely to have a dentist and rely on community dental services if residence was in a noninstitutionalized setting, compared with their counterparts living in an institution (Tiller, Wilson, & Gallagher, 2001). Freedman and Chassler (2004) reported that adults with ID living with parents or relatives were least likely to visit a dentist within the previous 6 months of the study (72%), compared with those living in community residences (82%) or institutional facilities (82%). In our study, living arrangement was not

associated with and dental care visits among young adults with or without ID. The association between residential factors and dental care use among individuals with ID is complicated by correlated factors, including but not limited to, severity of ID, co-occurring conditions, employment, and dental insurance. Further exploration of these associations is warranted.

Our finding that young adults with ID with limitations in ADLs were more likely to have at least one or two dentist visit per year, compared with young adults with ID without limitations in ADLs, needs further exploration. Limitations in ADLs among persons with severe ID have been reported to influence their ability to seek assistance for their dental needs in one study from Japan (Chiwata & Takeda, 2007), but this association was based on a limited sample of individuals. Also, the association between ADLs among persons with ID and dental care frequently can be interrelated with presence of other co-occurring DDs (Harries, Guscia, Nettelbeck, & Kirby, 2009). No other studies among young adults with ID have examined the association between ADLs or IADLs and dental care use for comparison. It is possible that young adults with ID, particularly with co-occurring conditions that have ADLs or IADLs, may receive assistance from caregivers to perform daily activities. This may also increase the likelihood of better dental care and regular receipt of dental services. Our evidence of activity limitations as significant mediators between ID and dental care highlight an area for intervention that might improve dental health. Examining the role of caregivers among young adults with ID with limitations in ADLs and IADLs may provide additional insight into these findings.

Dental care insurance plays an important role in one's ability to obtain dental services regardless of disability status. Individuals without dental insurance, particularly those from lower socioeconomic backgrounds, are less likely to visit a dentist (Guay, 2004). For Medicaid recipients, reimbursement for all dental services is mandated for children and adolescents from birth to age 21 years (CMS, 2011). Despite this easily available reimbursement mechanism, only 20% of Medicaid-eligible children receive preventative dental care by age 20 (Waldman & Perlman, 1997). Medicaid reimbursements for dental services become elective after age 21, where each state covers only selected dental services for eligible adults, some ranging from comprehensive care to just emergency services (Waldman & Perlman, 2004). In Georgia, Medicaid reimbursements are available for eligible adults, but restricted to emergencies (e.g., tooth extractions [GDCH, 2011]). Approximately half of young adults with ID in our study had Medicaid as their dental insurer, whereas one-fourth had HMO or private insurance, and another quarter paid for dental care with their own or borrowed money. Denial of care among those with Medicaid is also a problem. Surveys conducted in Alabama (Al Agili, Roseman, Pass, Thornton, & Chavers, 2004) and Tennessee (Valet, Kutny, Hickson, & Cooper, 2004) determined that families of special needs children with Medicaid were less likely to visit a dentist, compared with their counterparts with private insurance because of denied access.

The association between having a toothache within 4 weeks before the interview and receipt of dental services among young adults with and without ID was determined as significant for at least one dental visit during a year among young adults with ID and isolated MID. One of the reasons for this association might be the higher incidence of toothache among

those with ID (Scott, March, & Stokes, 1998), and that young adults with ID are highly vulnerable to lack of adequate preventative dental care, which might be a result of the absence of dental insurance. The toothache might also serve as an indicator of poor dental care. Future studies may have to prospectively evaluate this association taking into consideration the temporality of dental care and dental problems among young adults with ID. The frequency and characteristics of acute dental conditions should be explored further among young adults to better understand their dental problems, timely preventative care, and therapy.

The role of severity of ID and presence of other co-occurring DDs on dental care use has not been explored among young adults. Institutionalization might have served as an important proxy for ID severity and presence of co-occurring DDs. However, recent shifts in community-based living and social integration of individuals with ID makes studying dental care visits challenging, particularly among young adults with mild and moderate ID. As more people with ID are integrated in the community, a greater gap might exist in meeting oral health needs and visiting a dentist, compared with those living in institutional settings (Tiller et al., 2001).

One of the strengths of our study is the population-based design and presence of interview questions related to dental care. The structured telephone interviews, conducted by trained interviewers, offered the opportunity to examine key dental care characteristics among young adults with and without ID for the first time. The MADDS surveillance data improved the diagnostic specificity and more complete ascertainment of young adults with ID, compared with other studies and allowed evaluation of dental care by severity of ID and co-occurring DDs. The questionnaire assessed crucial demographic, lifestyle, and health care variables, allowing multivariable models with potential co-factors. Findings from the study provide valuable information and can help generate new hypotheses for future investigation.

Our study was also subject to limitations. The MADDS Follow-Up cohort might not have represented the more current generation of young adults. The interview responses may have potential recall error and responses related to dental visits cannot be validated. Our study was unable to examine additional factors that might have contributed to disparities in dental care visits. Only 5% of young adults without ID in our study reported Medicaid as their primary source of dental care insurance, compared with 25% of Medicaid enrollees among the general population (Vivier, 2005). Thus, Medicaid dental insurance prevalence in the current study might not be representative of general population. The association between having Medicaid insurance and reporting two or more dental care visits per year by young adults with and without ID in our study should be interpreted with caution. The cross-sectional analysis limited our ability to analyze temporality in some of the observed associations, for example, it was hard to determine the accurate role of toothache during the period prior to the interview as an indicator for receipt of dental care, considering the possibility that the toothache in itself may be a result of poor dental care.

Our results have implications for national objective planning regarding dental care, both among individuals with and without ID. The oral health objective of *Healthy People 2020* is

to increase the proportion of children, adolescents, and adults who use the dental care system (USDHHS, 2011). In particular, the 2008 National Dental Summary report proposed to raise the proportion of children, adolescents, and adults who use the dental care system within a year from 45% to 56% (USDHHS, 2008). We believe that the results from our study will further our understanding of dental care usage and needs among young adults with ID and without ID, identify areas for intervention, and help work toward the goal of increasing the proportion of young adults using dental care systems every year.

For a child with ID, the latest estimate for excess lifetime costs above costs incurred for a typically developing child is close to one million in 2003 U.S. dollars (Honeycutt et al., 2004). However, this might be an underestimate, because lifetime medical costs for individuals with ID have limited measures for quantifying dental care, and thus might result in omission of these services from current estimates (Honeycutt et al., 2004). Because periodic dental care thwarts progression of periodontal disease in young adults, particularly among those with disabilities (Yoshihara, Morinushi, Kinjyo, & Yamasaki, 2005), accessing care early in life can significantly reduce lifetime costs associated with ID (Glassman & Folse, 2005; Savage, Lee, Kotch, & Vann, 2004). With an aging cohort of children and young adults with ID facing other health problems stemming from untreated or poorly treated dental conditions, access and use of dental care at an early age should be an attainable priority (Hennequin, Faulks, & Roux, 2000).

5. Conclusion

In summary, our study identified a statistically significant disparity in dental care visits among young adults with and without ID. Young adults transitioning from pediatric to adult dental care face unique challenges regarding dental care. Changing living conditions, lack of dental insurance, and disappearance of community-based programs that cater to preventative care might force young adults to neglect dental care. These young adults should be identified, particularly those who do not have a high school education and who are not receiving vocational services, and information should be provided to their caregivers regarding resources for improving their dental care. Targeting dental services to young adults by increasing awareness and improving resources can help to reduce overall costs associated with delayed treatments, as well as restorative or emergency dental care. Finally, legislative policies that promote recommended dental care among young adults, particularly those with disabilities might help improve use among younger populations.

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Table 1

Characteristics of young adults with and without intellectual disabilities (ID)—Metropolitan Atlanta Developmental Disabilities Surveillance Follow-Up Study.

Characteristics	ID *n* = 244%	Isolated MID *n* = 117%	Isolated MPID *n* = 73%	Multiple ID *n* = 54%	No ID *n* = 124%
Demographic variables					
Sex					
Female	41.0*	37.6*	49.3	37.0*	54.8
Male	59.0	62.4	50.7	63.0	45.2
Race					
Non-Hispanic white	41.9*	37.1*	35.2*	61.1	64.5
Non-Hispanic black	58.1	62.9	64.8	38.9	35.5
Age at interview (years)					
22–23	45.1*	44.4*	50.7*	38.9*	71.8
24–25	54.9	55.6	49.3	61.1	28.2
SES—income-dependent services					
No	82.8	77.8*	84.9	90.7	87.9
Yes	17.2	22.2	15.1	9.3	12.1
Education					
Less than high school	27.1*	37.6*	13.7*	22.2*	11.3
High school graduate/GED	70.9	59.0	86.3	75.9	25.0
Postsecondary education	2.0	3.4	0	1.9	63.7
Employment					
Yes	36.5*	49.6*	27.4*	20.4*	85.5
No	63.5	50.4	72.6	79.6	14.5
Vocational services					
No	59.0*	53.8*	72.6*	51.9*	29.0
Yes	41.0	46.2	27.4	48.1	71.0
Living arrangement					
Independent	15.6*	28.2*	5.5*	1.9*	66.9
Other	84.4	71.8	94.5	98.1	33.1

Characteristics	ID *n* = 244%	Isolated MID *n* = 117%	Isolated MPID *n* = 73%	Multiple ID *n* = 54%	No ID *n* = 124%
Limitations in ADLs					
No	66.4*	91.5*	63.0*	16.7*	98.4
Yes	33.6	8.6	37.0	83.3	1.6
Limitations in IADLs					
No	28.7*	52.1*	9.6*	3.7*	91.9
Yes	71.3	47.9	90.4	96.3	8.1
Dental visits—at least 1 per year					
No (<1/year)	54.9*	71.8*	43.8	33.3	41.9
Yes (≥1/year)	45.1	28.2	56.2	66.7	58.1
Dental visits—at least 2 per year					
No (<2/year)	74.6*	86.3*	69.9	55.6	59.7
Yes (≥2/year)	25.4	13.7	30.1	44.4	40.3
Dental services					
Location dental care received					
No care received	24.5*	36.1*	20.6*	5.7*	13.8
Private/family dentists	53.3	47.2	55.9	62.3	78.9
Public health/institutional clinic	21.4	14.8	23.5	32.0	4.9
Dental maintenance organization	0.8	1.9	0	0	2.4
Dental care insurance					
HMO/private insurance	25.1*	31.0*	17.7*	22.5*	53.5
Personal (own or borrowed)	27.0	36.0	17.7	20.4	37.7
Medicaid/state or county funds	47.9	33.0	64.5	57.4	8.8
Dental health					
Toothache (previous 4 weeks)					
No	89.3	85.3	93.1	92.6	88.6
Yes	10.7	14.7	6.9	7.4	11.4
Gum bleed (previous 4 weeks)					
No	87.2*	85.3*	87.5	90.7	94.3
Yes	12.8	14.7	12.5	9.3	5.7

GED, general educational development; Iso_MID, isolated mild intellectual disability; Iso_MPID, isolated moderate to profound intellectual disability; ID, Iso_MID + Iso_MPID + multiple ID; SES, socioeconomic status; HMO, health maintenance organization.

*Young adults with ID significantly different from young adults without ID (*P* value < 0.05).

Table 2

Dental visits among young adults with or without intellectual disabilities, by severity level and presence of co-occurring developmental disabilities—Metropolitan Atlanta Developmental Disabilities Surveillance Follow-Up Study.

Severity level	<1 dental visit/year versus ≥1 dental visit/year				<2 dental visit/year versus ≥2 dental visit/year			
	<1 visit/yr *n* = 186	≥1 visit/yr *n* = 182	cOR (95% CI)	aOR* (95% CI)	<2 visits/yr *n* = 256	≥2 visits/yr *n* = 112	cOR (95% CI)	aOR* (95% CI)
No ID	52	72	Ref	Ref	74	50	Ref	Ref
ID	134	110	2.1 (1.4–3.2)	1.0 (0.4–2.4)	182	62	2.5 (1.7–3.8)	1.3 (0.6–3.0)
Isolated MID	84	33	3.5 (2.1–5.7)	1.2 (0.5–3.1)	101	16	4.3 (2.4–7.8)	1.9 (0.7–4.8)
Isolated MPID	32	41	1.1 (0.7–1.8)	1.5 (0.4–6.2)	51	22	1.6 (0.9–2.6)	3.1 (0.8–12.2)
Multiple ID	18	36	0.7 (0.4–1.3)	4.7 (0.7–33.4)	30	24	0.9 (0.5–1.5)	0.7 (0.1–5.1)

aOR, adjusted odds ratio; CI, confidence interval; cOR, crude odds ratio; ID, intellectual disability; MID, mild intellectual disability; MPID, moderate to profound intellectual disability; Ref, Reference.

<1 dental visit/year versus ≥1 dental visit/year = at least one dental visit per year versus fewer than one dental visit per year.

<2 dental visit/year versus ≥2 dental visit/year = at least two visits per year versus fewer than two dental visits per year.

*Adjusted for sex, race/ethnicity, age at interview, socioeconomic status, education, employment, vocational services, living arrangement, limitations in ADLs, limitations in IADLs, location where dental care received, dental care insurance, toothache gum bleed (within previous 4 weeks).

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Table 3

Unadjusted analyses: Predictors for at least one or two dental visit per year among young adults with and without intellectual disabilities—Metropolitan Atlanta Developmental Disabilities Surveillance Follow-Up Study.

Characteristics	<1 dental visit/year versus ≥1 dental visit/year			<2 dental visit/year versus ≥2 dental visit/year		
	ID cOR (95% CI)	Isolated MID cOR (95% CI)	No. ID cOR (95% CI)	ID cOR (95% CI)	Isolated MID cOR (95% CI)	No. ID cOR (95% CI)
Demographic variables						
Sex						
Female	Ref	Ref	Ref	Ref	Ref	Ref
Male	1.67 (1.02–2.75)	1.13 (0.52–2.43)	3.70 (1.87–7.34)	1.84 (1.05–3.21)	1.42 (0.52–3.82)	3.95 (1.93–8.06)
Race/ethnicity						
Non-Hispanic white	Ref	Ref	Ref	Ref	Ref	Ref
Non-Hispanic black	1.71 (1.04–2.81)	1.34 (0.62–2.90)	3.00 (1.50–6.01)	1.95 (1.11–3.41)	0.94 (0.34–2.62)	2.41 (1.17–4.99)
SES-income-dependent services						
No	Ref	Ref	Ref	Ref	Ref	Ref
Yes	2.37 (1.16–4.82)	1.77 (0.66–4.77)	0.91 (0.34–2.49)	2.20 (0.86–5.63)	1.18 (0.34–4.09)	2.01 (0.67–6.03)
Education						
Less than high school	3.83 (2.19–6.71)	13.53(3.39–53.93)	1.07 (0.34–3.37)	4.49 (2.19–9.20)	–	2.86 (0.62–13.18)
High school graduate/GED	Ref	Ref	Ref	Ref	Ref	Ref
Postsecondary education	0.12 (0.02–0.87)	0.10 (0.01–0.97)	0.65 (0.30–1.40)	0.05 (0.01–0.33)	0.03 (0.004–0.33)	0.51 (0.23–1.14)
Employment						
Yes	Ref	Ref	Ref	Ref	Ref	Ref
No	1.35 (0.82–2.21)	3.01 (1.36–6.66)	0.86 (0.34–2.19)	1.20 (0.68–2.12)	3.29 (1.09–9.97)	1.07 (0.42–2.73)
Vocational services						
No	Ref	Ref	Ref	Ref	Ref	Ref
Yes	0.41 (0.25–0.68)	0.27 (0.12–0.62)	0.60 (0.29–1.26)	0.29 (0.16–0.53)	0.06 (0.01–0.42)	0.67 (0.33–1.37)
Limitations in ADLs						
No	Ref	Ref	Ref	Ref	Ref	Ref
Yes	0.42 (0.25–0.69)	3.63 (0.52–25.48)	–	0.41 (0.24–0.71)	–	0.67 (0.05–8.60)
Dental Services						
Dental care insurance						
HMO/Private Insurance	Ref	Ref	Ref	Ref	Ref	Ref

Characteristics	<1 dental visit/year versus ≥1 dental visit/year			<2 dental visit/year versus ≥2 dental visit/year		
	ID cOR (95% CI)	Isolated MID cOR (95% CI)	No. ID cOR (95% CI)	ID cOR (95% CI)	Isolated MID cOR (95% CI)	No. ID cOR (95% CI)
Personal (own or borrowed)	1.33 (0.65–2.73)	1.35 (0.54–3.40)	3.02 (1.43–6.35)	0.88 (0.42–1.84)	0.75 (0.25–2.28)	2.85 (1.33–6.10)
Medicaid/State/County funds	1.49 (0.79–2.81)	2.47 (0.89–6.81)	0.60 (0.13–2.68)	2.53 (1.24–5.19)	3.27 (0.69–15.62)	1.66 (0.48–5.73)
Dental health						
Toothache (previous 4 weeks)						
No	Ref	Ref	Ref	Ref	Ref	Ref
Yes	2.87 (1.20–6.89)	3.47 (0.84–14.33)	0.76 (0.26–2.19)	1.50 (0.56–4.03)	1.22 (0.28–5.25)	0.65 (0.24–1.80)

ADLs, activities of daily living; CI, confidence interval; cOR, crude odds ratio; GED, general educational development; HMO, health maintenance organization; IADLs, instrumental activities of daily living; Ref, Reference; SES, socioeconomic status.

<1 dental visit/year versus ≥1 dental visit/year = at least one dental visit per year versus fewer than one dental visit per year.

<2 dental visit/year versus ≥2 dental visit/year = at least two visits per year versus fewer than two dental visits per year.

cORs and 95% CIs were not statistically significant in any of the case or control groups, and hence, not presented for the following study variables: age at interview, living arrangement, limitations in IADLs, location where dental care received, and gum bleed during the previous 4 weeks.

Some cORs and 95% CIs were not calculated because of insufficient cells.

Table 4

Multivariable analysis for factors influencing one or two dental visits among young adults with and without intellectual disabilities—Metropolitan Atlanta Developmental Disabilities Surveillance Follow-Up Study.

Characteristics	<1 dental visit/year versus ≥1 dental visit/year			<2 dental visit/year versus ≥2 dental visit/year		
	ID aOR (95% CI)[a]	Isolated MID aOR (95% CI)[a]	No ID aOR (95% CI)[a]	ID aOR (95% CI)[a]	Isolated MID aOR (95% CI)[a]	No ID aOR (95% CI)[a]
Demographic variables						
Sex						
Female	Ref	Ref	Ref	Ref	Ref	Ref
Male	2.80 (1.44–5.45)	2.73 (0.73–10.24)	4.27 (1.80–10.12)	2.59 (1.23–5.43)	1.86 (0.30–11.54)	4.92 (2.12–11.44)
Race/ethnicity						
Non-Hispanic white	Ref	Ref	Ref	Ref	Ref	Ref
Non-Hispanic black	1.17 (0.63–2.16)	1.43 (0.49–4.19)	4.30 (1.61–11.50)	1.09 (0.56–2.14)	0.29 (0.07–1.20)	2.02 (0.83–4.91)
Education						
Less than high school	2.99 (1.59–5.63)	14.63 (2.96–72.32)	2.35 (0.52–10.60)	3.16 (1.42–7.02)	–	4.52 (0.63–32.42)
High school graduate/GED	Ref	Ref	Ref	Ref	Ref	Ref
Postsecondary education	–	–	1.07 (0.40–2.86)	–	–	0.73 (0.30–1.79)
Vocational services						
No	Ref	Ref	Ref	Ref	Ref	Ref
Yes	0.43 (0.22–0.82)	0.55 (0.18–1.65)	0.25 (0.09–0.66)	0.27 (0.13–0.55)	0.04 (0.004–0.51)	0.36 (0.14–0.92)
Limitations in ADLs						
No	Ref	Ref	Ref	Ref	Ref	Ref
Yes	0.28 (0.14–0.59)	3.56 (0.27–46.56)	–	0.22 (0.10–0.53)	–	0.23 (0.03–1.57)
Dental Services						
Dental care insurance						
HMO/private insurance	Ref	Ref	Ref	Ref	Ref	Ref
Personal (own or borrowed)	0.92 (0.41–2.08)	0.57 (0.17–1.87)	2.52 (1.07–5.94)	0.60 (0.26–1.41)	0.42 (0.11–1.65)	2.68 (1.13–6.36)
Medicaid/State/County funds	1.32 (0.58–3.03)	0.86 (0.17–4.30)	0.32 (0.07–1.50)	3.51 (1.33–9.25)	8.65 (0.95–78.96)	1.07 (0.24–4.80)
Dental health						
Toothache (previous 4 weeks)						
No	Ref	Ref	Ref	Ref	Ref	Ref

Characteristics	<1 dental visit/year versus ≥1 dental visit/year			<2 dental visit/year versus ≥2 dental visit/year		
	ID aOR (95% CI)[a]	Isolated MID aOR (95% CI)[a]	No ID aOR (95% CI)[a]	ID aOR (95% CI)[a]	Isolated MID aOR (95% CI)[a]	No ID aOR (95% CI)[a]
Yes	3.45 (1.44–8.25)	6.51 (1.22–34.77)	0.87 (0.27–2.80)	1.59 (0.55–4.55)	0.52 (0.07–3.66)	0.75 (0.24–2.34)

ADLs, activities of daily living; aOR, adjusted odds ratio; CI, confidence interval; GED, general educational development; HMO, health maintenance organization; ID, intellectual disability; MID, mild intellectual disability; Ref, Reference.

<1 dental visit/year versus ≥1 dental visit/year = at least one dental visit per year versus fewer than one dental visit per year.

<2 dental visit/year versus ≥2 dental visit/year = at least two visits per year versus fewer than two dental visits per year.

Some aORs and 95% CIs were not calculated because of insufficient cells.

[a]Each variable was adjusted for all other variables within the respective column, and for socioeconomic and employment status.